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COOLEY'S ANEMIA: PREVENTION THROUGH TESTING

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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
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COOLEY'S ANEMIA: PREVENTION THROUGH TESTING

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Do you have Cooley's anemia? Maybe you do . . . and don't know it. Cooley's anemia is a fatal blood disease that is passed from parent to child; it strikes children of Mediterranean-American parents—Italian and Greek Americans, as well as Americans of Syrian, Israeli, and other ancestry.

Despite great advances in understanding the disease and in developing treatments for it, severe Cooley's anemia always kills its victims. No cure has been found.

If you've been healthy, you know by now that you don't have the severe form of the disease. But there are several types of anemias related to Cooley's anemia. Some types are so mild that you may never know you are carrying the trait that could cause the fatal form of the disease in your children. All forms of the disease, as well as the trait itself, are hereditary and can, therefore, be passed by one or both parents to their children.

Children born with the severe form of the disease die prematurely. They appear healthy at birth; it is within the first year of life that their physicians detect Cooley's anemia. The children produce red blood cells that are damaged and do not function properly. They become anemic and begin needing monthly blood transfusions to combat their anemia. These constant transfusions result in an iron imbalance in their systems—an imbalance that eventually causes fatal damage to such vital organs as the heart and liver.

The inescapable genetic facts are these: when **both parents have the trait** for Cooley's anemia, there is a one-in-four chance that **each pregnancy** will produce a child with fatal Cooley's anemia. This means that a couple can have more than one child with the disease. Even when parents with the trait don't give birth to a baby with the major form of the disease, they may have passed the trait to their children.

Who should be concerned about this devastating disease? Anyone of Mediterranean descent should realize that the odds are real that he or she may be carrying the trait for Cooley's anemia. Estimates

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are that somewhere between 50,000 and a million Italian and Greek Americans are carrying the trait and **don't know it**. Too many young people feel that they have no reason to be concerned because they have not been sick or because Cooley's anemia has not appeared in their families. They do not realize that **members of their families may be carrying the trait without any evidence of the disease** or with only a mild form of anemia. Others may believe that if they are carrying the trait it will show in the routine blood test required for a marriage license. This is not the case.

According to the Cooley's Anemia Foundation, a young couple usually hears about the disease for the first time when the doctor tells them that their baby has Cooley's anemia . . . and will die prematurely! Then they ask: "Why didn't someone tell us we were carrying the trait?"

If you are of Mediterranean descent, there is only **one way** to be sure that you are free of the Cooley's anemia trait, and that is to have a proper blood test taken by your physician. You must ask for such a test. Do not assume that your doctor will automatically test for the disease because you may have an Italian or Greek name or because he's familiar with your family history. Remember that under normal circumstances your blood will **never** be tested for the Cooley's anemia trait UNLESS YOU ASK FOR SUCH A TEST.

No parents would consciously inflict a fatal and devastating disease on their children. But until research into the cause and treatment of Cooley's anemia produces a cure, **prevention of the disease** is possible only if people seek a blood test. For those who go untested, there is the possibility that their lives and the lives of those they love most will be shattered. For those who have the test, there will be either relief from tremendous concern or the opportunity to help break the chain of a disease that has caused untold grief for far too long.

If you are of Mediterranean descent, it is up to you to seek the necessary testing: the first crucial step in the prevention of Cooley's anemia.

If you are interested in testing or genetic counseling related to Cooley's anemia, contact your physician; any major medical center; the Cooley's Anemia Foundation, Incorporated; the Ahepa Cooley's Anemia Foundation; or your local chapter of the National Foundation-March of Dimes. You may also wish to write or call the National Clearinghouse for Genetic Diseases of the Health Services Administration, U.S. Public Health Service, 1776 East Jefferson Street, Rockville, Maryland 20852, telephone (301) 279-4642.

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